

WOMEN AND HIV/AIDS IN LESOTHO:
LINKING SOCIAL AND STRUCTURAL DRIVERS, POLICY,
AND HUMAN RIGHTS

by

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Abstract

The Kingdom of Lesotho has the third highest HIV/AIDS prevalence rate in the world currently estimated at 23.6%. Women in Lesotho are disproportionally infected with HIV, accounting for 56% of the national cases. Social and structural factors that create gender inequality and violence against women have been identified as key drivers of the epidemic. This paper examines social structural drivers of HIV/AIDS in Lesotho pertaining to women's empowerment: gender inequality; GBV; and human rights violations. These drivers are explored through an examination of Lesotho's laws, commitments to international protocols and declarations, and attitudes of Lesotho's people (Basotho) toward sexual negotiation and GBV. In addition to creating an environment where women are more vulnerable to acquiring HIV infection, these factors have been identified as barriers to HIV testing in the region where women are often disclosing HIV test results to an untested partner, leaving them vulnerable to violence and abandonment. International HIV testing guidelines and national policies that implement routine testing and de-emphasize pre-test counseling may reinforce these social structural drivers and negatively affect the human rights of Basotho women. National HIV testing policies of Lesotho are analyzed through a human rights framework and linkages of these policies and social structural factors of the HIV/AIDS epidemic are explored.

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I. Introduction

Sub-Saharan Africa (SSA) bears the greatest burden of the global HIV/AIDS pandemic, accounting for 68.7% of the world's infections, and contains the highest number of people living with HIV/AIDS (PLWHA) at an estimated 23.5 million, five times as many as any other region in the world (1). Located within this region is the Kingdom of Lesotho where there HIV/AIDS prevalence rate is currently estimated at 23.6% (1). The vulnerability of women and girls to HIV is critically important in the region, with about 76% of all HIV positive women in the world residing in SSA. Consistent with these findings, women in Lesotho are disproportionately infected with HIV, accounting for 56% of the national cases (2). Consistent with other countries in the region, Lesotho is currently experiencing both a generalized and highly gendered HIV/AIDS epidemic. Social and structural factors that create gender inequality and violence against women have been identified as key drivers of the epidemic. The Joint United Nations Programme on HIV/AIDS (UNAIDS) has declared that all forms of gender-based violence (GBV) and discrimination against women and girls should be recognized as both human rights violations and elements that can increase vulnerability to HIV infection (3).

This paper will examine social structural drivers of HIV/AIDS in Lesotho pertaining to women's empowerment: gender inequality; GBV; and human rights violations. These drivers will be explored through an examination of Lesotho's laws, commitments to international protocols and declarations, and attitudes of Lesotho's people (Basotho) toward sexual negotiation and GBV. In addition to creating an environment where women are more vulnerable to acquiring HIV infection, these factors have been identified as barriers to HIV testing in the region where women are often disclosing HIV test results to an untested partner, leaving them vulnerable to violence and abandonment. International HIV testing guidelines and national

policies that implement routine testing and de-emphasize pre-test counseling may reinforce these social structural drivers and negatively affect the human rights of Basotho women. This paper also analyzes national HIV testing policies in Lesotho through a human rights framework and explores linkages of these policies and social structural factors of the HIV/AIDS epidemic.

II. Lesotho

“There are two types of people in Lesotho; those infected and those affected by HIV/AIDS.”

-Care Lesotho (2004)(2)



Figure 1: Political Map of Lesotho (4)

Lesotho is a mountainous kingdom completely surrounded by South Africa (See Figure

1). An independent, democratic nation for 47 years, Lesotho is governed by a parliamentary

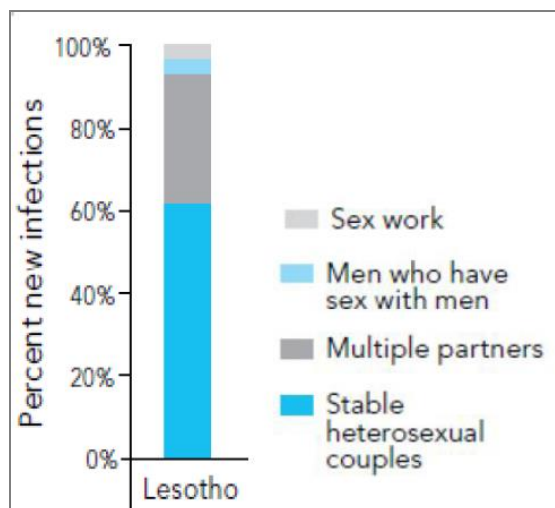
constitutional monarchy ruled by His Majesty King Letsie III with daily leadership provided by a multi-party National Assembly, according to the provisions of the constitution. Lesotho relies heavily on assistance from development partners as well as inflow of remittances from migrant workers and receipts from the Southern African Customs Union which together account for 60% of the government's annual budget (5). Lesotho ranks among the 48 least developed countries in the world. In 2011, Lesotho ranked 160 out of 187 countries on the United Nations Development Program's (UNDP) Human Development Index (HDI) (6).

The ecological terrain of Lesotho divides the country into four main regions: lowlands; foothills; mountains; and the Senqu River Valley which encompass all ten administrative districts. Lesotho implements a decentralized, local governance structure through 74 local community councils which are administered through these districts (5). Most districts have a combination of terrains with the exception of Mokhotlong, the entirety of which is mountainous. This is important to note due to the geographical isolation that is experienced by the inhabitants of the rural, mountainous areas. An estimated 77% of the population lives in these remote, mountainous locations, while 23% of the population lives in the urban areas clustered around the northern borders near South Africa (5). The life expectancy at birth is currently estimated at 52 years (7). Almost 60% of the population is under 19 years old (5). Lesotho has one of the lowest population growth rates in the region at 0.33. The impact of the HIV epidemic has been cited as a major factor in the country's population decline (5).

The HIV prevalence in Lesotho is currently estimated at 23.6%. HIV/AIDS was declared a national disaster by King Letsie III in 2003 (5). Prevalence rates have held at this level since 2005, signaling a continued stabilization of the epidemic (8). Districts with the highest prevalence rates are Maseru (27%), Maseru's Hoek (24%) and Leribe (24%). Districts with the

lowest prevalence rates are Thaba-Tseka (20%) and Buthe-Buthe (16%) (9). However, gender disparities in HIV prevalence remain: 26.7% of all adult women are HIV-positive as compared to

Figure 2: New infections by mode of transmission



Data from UNAIDS (3)

18% of all adult men; and approximately 60% of all HIV-positive adults and children are female

(5). Figure 2 shows the percentage of new HIV infections in Lesotho by mode of transmission; demonstrating that horizontal transmission between stable heterosexual couples accounts for over half of all new infections. A 2009 report by the Southern Africa Development Community (SADC) states that national development

indicators for the country conceal significant

gender and geographical disparities in the realization of gender equality and human rights (10).

III. Women and HIV in Southern Africa

“If it can be said, as it can, that by the year 2020, the number of deaths from AIDS in Africa will approximate the number of deaths, military and civilian combined, in both world wars of the 20th century, then it should also be said that a pronounced majority of those deaths will be women and girls. The toll on women and girls is beyond human imagining; it presents Africa and the world with a practical and moral challenge which places gender at the centre of the human condition. The practice of ignoring a gender analysis has turned out to be lethal. . . .For the African continent, it means economic and social survival. For the women and girls of Africa, it's a matter of life or death.”

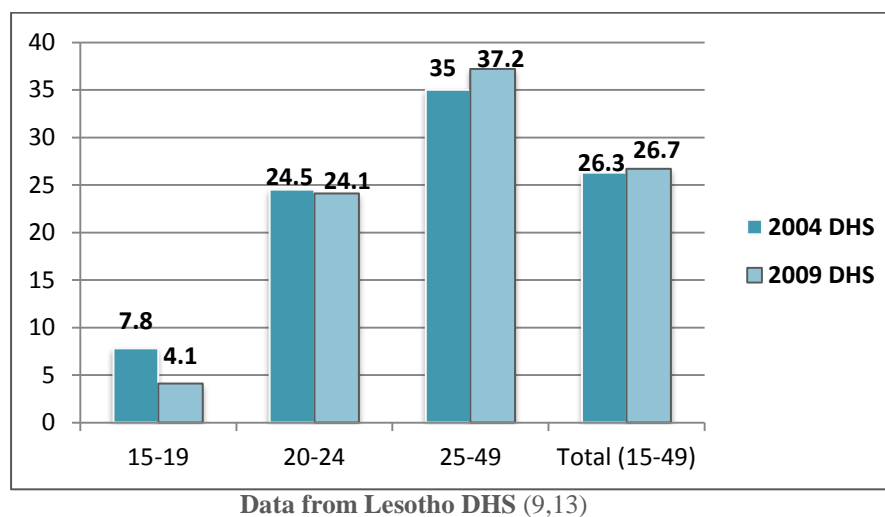
-Stephen Lewis, U.N. Secretary-General's Special Envoy on HIV/AIDS in Africa, July 2002 (11)

The 2012 UNAIDS report, *Together We Will End AIDS*, estimates that there were 34.2 million PLWHA globally in 2011. SSA bears the greatest burden of the global HIV/AIDS pandemic. The region accounts for 68.7% of the world's infections and contains the highest number of PLWHA at an estimated 23.5 million, five times as many as any other region in the world (1). There is considerable variation within the region. The epidemic remains most severe in the Southern Africa sub-region, where one-third of all PLWHIV globally reside in ten countries with generalized epidemics. The three highest prevalence rates in the world continue to be in the countries of Swaziland (25.9%), Botswana (24.8%) and Lesotho (23.6%) (12). South Africa, with an estimated 5.4 million-5.8 million HIV-positive people, continues to have the world's largest HIV epidemic (1). The majority of people newly infected with HIV in SSA acquire the virus during unprotected heterosexual intercourse (horizontal transmission) or as newborn and breastfed babies (vertical transmission). Southern Africa is projected to fall short of Millenium Development Goal 6 which aims to halt and reverse the spread of HIV/AIDS by 2015. The region has already failed to meet another target—the acheivement of universal access to treatment for all those infected with HIV by 2010.

The vulnerability of women and girls to HIV remains of critical importance, with about 76% of all HIV positive women in the world residing in SSA. HIV prevalence data in 2010 revealed that in SSA, 13 women become infected for every 10 men infected (12). Consistent with these findings, women in Lesotho are disproportionally infected with HIV, accounting for 56% of the national cases. Girls and women between the ages of 15-24 years are particularly at risk, shown by prevalence rates that are consistently higher than their male counterparts. In Lesotho, 71% of those infected in this age cohort are female (2). Figure 3 illustrates HIV prevalence rates among Basotho women by age group. The overall prevalence rates for women

in the country have remained consistent from 2004 to 2009, as demonstrated through findings from the Lesotho Demographic and Health Survey (DHS) taken in those years at 26.3% and 26.7%, respectively (9,13).

Figure 3: HIV prevalence among the general female population in Lesotho (15-49 years)



In a region where the majority of adults become infected through unprotected sexual intercourse, these young women are particularly vulnerable due to physiological differences which increase their susceptibility for acquiring HIV infection. Furthermore, behavioral and structural factors contribute to these differentials. Behavioral factors include: intergenerational sex; low and inconsistent condom use; and having multiple, concurrent sexual partners (14). Structural factors include: cultural expectations of gender roles and marriage customs; economic dependency upon men; limited access to education and employment; legal status of women (including laws surrounding inheritance, divorce, child custody, and property ownership); legal definitions of rape; and political power of women in government (15). Thirty years into the HIV/AIDS pandemic, there is increased recognition that a shift from an emergency response to a

long-term one requires intervention strategies to move from targeting individuals to a more comprehensive approach which include social and structural factors (16). However, as UNAIDS reported in 2011, most funding dedicated to women is allocated towards antiretroviral therapy (ART) to prevent vertical transmission and not the full range of women's vulnerabilities (3).

IV. Social/Structural Drivers in Lesotho pertaining to women's empowerment

"Countries should ensure a massive political and social mobilization to address gender inequities, sexual norms, and their roles in increasing HIV risk and vulnerability"

-UN Secretary-General Ban Ki-moon, 1 April, 2008 (17)

Gender Inequality

Gender inequalities were identified over a decade ago as a fundamental driver of HIV, and epidemiological data still demonstrates a gendered epidemic in Southern Africa. Gender roles and relations have been identified as key to understanding the nature of the HIV/AIDS epidemic (17). In Lesotho, as in other Southern African countries, gender inequality has hampered HIV/AIDS prevention efforts. Social/structural factors such as poverty, gender inequality, and human rights violations that increase people's vulnerability to HIV infection are difficult to both define and measure. Additionally, identified social/structural factors that may enable GBV are similar to those identified drivers of HIV infection previously defined. They include: cultural definitions of gender roles and marriage customs; economic factors including a women's dependence upon men; limited access to employment and education opportunities; legal

definitions of rape, divorce and child custody laws; inheritance laws; and women's representation in government (15).

The 2011 United Nations General Assembly Special Session (UNGASS) Country Report for Lesotho identifies social and cultural factors affecting women and girls as a primary structural driver of the gendered epidemic in the country. The National AIDS Commission (NAC), the Government of Lesotho's coordinating body for HIV/AIDS multi-sectoral programming, identified gender inequality and GBV as a driver of the epidemic in the country stating they are "promoted by the low socioeconomic and legal positions of women where they are not empowered to make decisions in their lives, thus, predisposing them to sexual abuse and violation of their rights and increased risk to HIV transmission" (5). Among these, it is reported that Lesotho continues to have troubling trends in discriminatory attitudes towards women and girls which fuel GBV (5). This is demonstrated by findings in the 2009 Lesotho DHS in which 37.1% of women and 47.9% of men agreed that there could be at least one reason for a husband to legitimately beat his wife. In the lowest wealth quintile, this rose to 55% of women and 59% of men (9).

At the core of gender dynamics and differences are issues of power inequalities which result in the subordination of women to men, distributing the power to the men over women (or female-identified people) (17). The health status of Basotho women is adversely affected by their minority status in society as well as religious and cultural beliefs (2). These factors make it difficult for them to negotiate for safer sex within a relationship. The cultural practice of paying a bride price, referred to as *labola* or *bohali*, is argued to further reinforce this notion that women are "owned" and thus, subservient to their husbands. *Lobola* is the provision of gifts in exchange for a bride and is required by customary law, which states that both father's must negotiate and

agree on the amount of payment (18). The payment usually takes the form of livestock or cash and the woman has no autonomy in the transaction. It also symbolizes a transfer of a woman's reproductive capacity to bear children from the woman's family to her husband's. Thereafter, it is said locally that *n'goana ke oa likhomo* (the child belongs to the cattle) (18).

Education and Employment

Literacy (defined as people over the age of 15 who can read and write) rates are high in Lesotho with an estimated 90% of the total population literate. Females in Lesotho have higher literacy rates than their male counterparts at 96% and 83%, respectively (7). Additionally, there is a predominance of female students across all levels of education including primary, secondary and university. This is attributable in part to high numbers of females in the population as well as high levels of male migration. It has been estimated that over 250,000 Basotho nationals regularly reside in South Africa, with labor migration the primary reason (2). However, despite higher levels of education, women continue to experience limited access to productive resources. This is a result of institutionalized patriarchal cultural norms and practices which benefit men (10). Basotho men are still considered to be the head of the family and key household decision makers, a patriarchal idea based in the customary and common laws which are enshrined in the country's constitution(2). Legal recognition of the rights of women in Lesotho has yet to influence ongoing social and cultural practices regarding female roles in marriage and sexual relationships (5).

V. Legal Status of Women in Lesotho

“Punitive laws, gender inequality, violence against women and other human rights violations continue to undermine national AIDS responses.”

-UN Secretary-General Ban Ki-moon (19)

Over the last decade, Lesotho has adopted a comprehensive framework promoting gender equality. However, legal changes do not always ensure gender protection. Despite recognition for having one of the highest levels of gender equity on the African continent, deeply engrained cultural gender norms and inequities are drivers of Lesotho’s HIV epidemic (20).

Lesotho applies both customary law (administered through traditional chief courts) and the general law side by side. In terms of marriage, both civil and customary (heterosexual) unions are legally recognized (2). In 2006, Lesotho passed the Legal Capacity of Married Persons Act which effectively eliminated de jure discrimination against women under formal (but not customary) law. The passing of the Legal Capacity of Married Persons Act was a pre-condition set by the Millennium Challenge Corporation (MCC) before moving forward with the Lesotho Compact signed the following year (21). The Compact was a five-year agreement between the MCC and Lesotho to fund specific programs targeted at reducing poverty and stimulating economic growth. Prior to the passage of this act, married women were relegated to the status of a minor during the lifetime of her husband and not allowed to enter legally binding contracts without his consent. The Legal Capacity of Married Persons Act grants married women the legal rights to make a will, sue for divorce, obtain loans without the consent of her husband, and enjoy full economic rights under the law. Since passage of the new law, the rights of women have substantially improved (22). However, the law does not provide for women's

inheritance and custody rights. Without supportive, enabling legal environments to support equality in property and inheritance rights, women in Lesotho will not achieve full economic and social empowerment. Widows who need to support their families may turn to transactional sex, sex work, or cross-border migration, which will lead to increased vulnerability to HIV infection.

While the Lesotho Constitution does provide for freedom from discrimination, it carves out an exception in matters involving the application of customary law, for example land allocation. The Amended Constitution of Lesotho (1993) provides protection of and the right of every citizen to own property, regardless of gender; but all its provisions, particularly those that affect women, are subject to Customary Law. This means that the Amended Constitution of Lesotho of 1993 is not above Customary Law when it comes to the rights of women. These constraints on women are prominent especially with regard to women married under Customary Law. This includes the majority of women, especially in the rural areas of the country (23). Although Lesotho signed onto the Convention of all Forms of Discrimination against Women (CEDAW), the dual customary and common laws encourage discrimination (24).

In 2003, Lesotho passed The Sexual Offenses Act which prohibits rape, including spousal rape, and mandates a minimum sentence of five years' imprisonment, with no option for a fine. There is no legislation prohibiting domestic violence, but general assault provisions under common law and customary law apply (23). The U.S. Department of State reports that courts have heard a number of rape and attempted rape cases, several of which resulted in convictions. However, few domestic violence cases are brought to trial. A 2009 report by SADC states that there is a need for more awareness about the existence of the law to ordinary Basotho, so they will be encouraged to report incidences knowing that the perpetrators will be brought before the

law (10). The Obama administration's 2011 Global Health Initiative Strategy for Lesotho calls for the gender policy to take statutes from the legal code to the community (20).

VI. Regional and International Protocols and Commitments

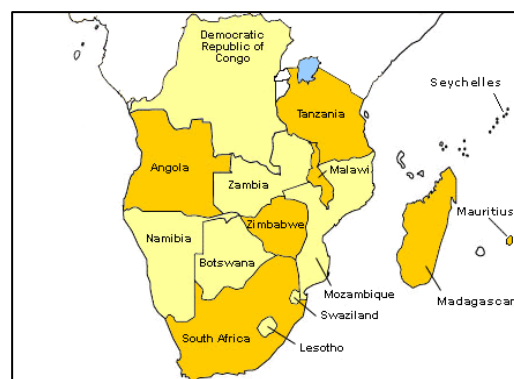
"The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. Equal relationships between women and men in matters of sexual relations and reproduction, including full respect for the integrity of the person, require mutual respect, consent and shared responsibility for sexual behaviour and its consequences."

-Paragraph 96, Beijing Platform for Action (25)

By ratifying various international treaties, resolutions, and declarations, governments are committed and accountable to implement them.

However, studies have indicated that adopted policies often remain on paper and are seldom implemented. Political leadership to implement new policies is still lacking in most countries and there are significant gaps between what is promised and what is delivered. A reported 123 Governments have done little to implement international human rights agreements that they have ratified for the advancement of women and more equitable gender relations (27).

Figure 4: SADC Member States



Map of SADC(26)

Lesotho has ratified and is signatory to many international commitments to advance the rights of women. Many of the legal advancements made for women in the country are comparable to other international initiatives. Lesotho is a member of SADC which is currently comprised of 15 countries from Eastern and Southern Africa (see Figure 4). The organization

has been legally governed for the past 20 years by the SADC treaty and works toward regional economic growth and stability, peace, security, social justice, and improved quality of life for all its citizens. In addition, these countries have committed to achieving regional integration of human rights—including the rights of women. The SADC Declaration on Gender and Development was ratified in support of this aim and declares to reaffirm the region's commitment to the Beijing declaration (28). This document resulted from the 1995 Beijing conference which pronounced that the human rights of women include the right to control their own sexual and reproductive health, and that women should be granted the freedom to make their own decisions from discrimination, coercion, and violence. In addition, all SADC member states have declared a commitment to improve accessibility of quality reproductive health services, protect and promote the human rights of women, and recognize, protect, and promote the reproductive and sexual rights of women and girls (28). Most recently, Lesotho signed the SADC Protocol on Gender and Development in 2008. This document aims to provide for the empowerment of women, to eliminate discrimination and achieve gender equality by encouraging the development and implementation of gender responsive legislation, policies, programs, and projects. The Government of Lesotho has a commitment to uphold these obligations and should keep these international commitments at the forefront of national HIV/AIDS policies and programs.

VII. Intersection of Violence and HIV

My husband hated condom use. He never allowed it. He used to beat me when I refused to sleep with him... He said 'when we are man and woman married, how can we use a condom?' ...It's a wife's duty to have sex with her husband because that is the main reason

you come together. But he didn't listen to me. I tried to insist on using a condom but he refused. So I gave in because I really feared [him].
 - *Woman from Uganda in Human Rights Watch Report (27)*

Violence has been clearly demonstrated as a risk factor for HIV (12,29-31). Violence can increase a woman's risk of acquiring HIV infection in three ways: through forced or coercive sexual intercourse with an infected partner; by limiting a woman's ability to negotiate safer sexual behaviors; and by establishing a pattern of sexual risk-taking for those who experience sexual assault in the period of childhood and adolescence (32). The second pathway illustrates the ways in which GBV and HIV infection goes beyond the associated physical risk factors (established biomedical increased risk of transmission associated with forced sex and dry sex), capturing the incapacity of women who fear violence from their partner to protect themselves from HIV infection.

Women who suffer from GBV and intimate partner violence (IPV) have a limited ability to negotiate safe sex or refuse unwanted sex, due to the fear and power differentials associated with violence and intimidation. Often times these women do not get tested for HIV and fail to seek treatment after infection occurs. GBV exacerbates structural gender inequalities and creates a choice disability for those affected. The term choice disabled refers to those whose needs are not currently addressed though current prevention methods (with the exception of post-exposure prophylaxis (PEP)), because they lack the power and agency to make decisions about whether to use existing methods of prevention, such as condoms (29). Condoms are widely promoted and distributed throughout the country by both the government and international non-governmental organizations (NGOs). One South African study demonstrated that women with less power had a lower likelihood of condom use, confirming an association between sexual power, relationship control, and condom use consistency (33).

The Lesotho DHS includes questions that gauge attitudes towards negotiating safer sex. Respondents were asked two questions: (1) if a woman is justified in refusing to have sex with her husband if she knows he has had sex with other women; and (2) if they think a woman in the same circumstances is justified in asking her husband to wear a condom if she knows that he has a sexually transmitted infection (STI) (9). The results for the first question were almost even with 52% of women and 53% of men affirming that a woman is justified in refusing sex with her husband if she knows he is having sex with another woman. A larger proportion of urban men and women responded this way. The results for the second question differed more by sex with 90% of women and 86% of men agreeing that a woman is justified in asking her husband to wear a condom if she knows he has a STI (9).

A study in South Africa found that an estimated one in seven cases in which women aged 15-26 years acquired HIV infection was associated with gender imbalances and IPV (34). Women in abusive relationships are at higher risk of infection regardless of their own sexual behaviors because men who perpetuate violence are themselves at higher risk of HIV and other STIs. Another South African study found that young men who perpetrate partner violence engage in significantly higher levels of risky behaviors associated with contracting HIV than non-perpetrators, and more severe violence is associated with higher levels of risky behavior (31).

In addition to being more at risk of infection, HIV positive women are also more likely to experience violence, from both an intimate partner and a community member, as a result of their infection status. A cross-sectional household survey in 2002 ascertaining risk factors for domestic physical violence found that having multiple partners had the strongest association with partner physical violence (increasing with number of partners); while other measured

variables (age, income, education, household size and occupation) had no significant association (35). Community-based studies in SSA have found that HIV positive women report experiencing GBV at higher rates than their HIV negative counterparts (36).

As in many other countries of the developing world, there is limited data available about sexual violence and its determinants in Lesotho (15). The 2002 Lesotho Reproductive and Health Survey found that 13% of male respondents (age 12-59) and 14% of female respondents (age 12-49) reported knowing someone who had been raped in the past 12 months (15). In January 2003, a midterm evaluation of a program implemented by CARE International aimed at intervening in HIV transmission on the household level was conducted by MEASURE Evaluation. Qualitative and quantitative data were collected in the urban centers of Maseru and Maputsoe (located in the northern district of Leribe) through focus groups, household surveys, and interviews. Results of the household survey of 949 women (aged 18-35) revealed that 31% reported that they had been touched against their will and 25% reported ever being physically forced to have sex. Additionally, 13% reported that forced sex had been attempted and 11% reported being forced to touch a man's genitals. These results included women from both the intervention and comparison groups (15).

The lack of data in Lesotho limits the picture of the associations between GBV and the HIV/AIDS epidemic there. Despite having the third highest HIV/AIDS prevalence rate in the world, research in Lesotho remains limited, especially compared with larger, neighboring countries of South Africa and Botswana. One author points out that considering the body of literature linking IPV, sexual risk-taking, HIV, and other STIs, there is a substantial gap in terms of large-scale, population-based studies conducted in SSA, particularly outside of South Africa (37).

Studies among women in SSA show the most commonly reported barriers to HIV testing and disclosure of status is fear of a partner's negative reaction. These include abandonment, violence, rejection, loss of economic support, and accusations of infidelity (38). Since testing serves as both a prevention tool as well as an entry point into HIV/AIDS care, treatment and support services, it is important to examine barriers to testing in particular countries and create a supportive legislative and policy environments to mitigate them.

VIII. HIV Testing in Lesotho

“It is critical that we expand access to HIV testing. But testing programs will fail if they do not also provide people protection from stigma, discrimination and abuse.”

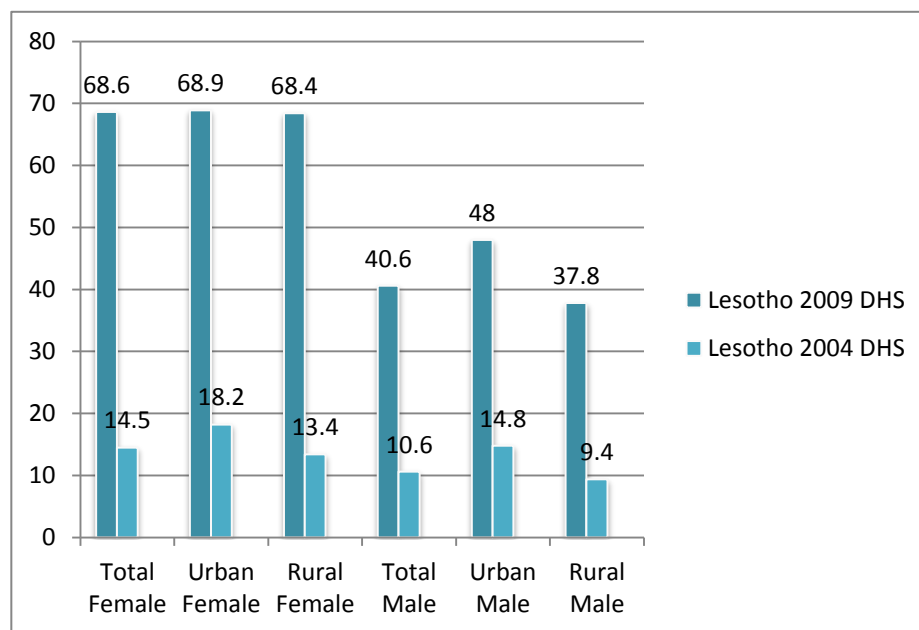
-Joe Amon, director of the HIV/AIDS program at Human Rights Watch(39)

History

In line with other SSA countries experiencing generalized HIV/AIDS epidemics, sentinel surveillance among pregnant women attending antenatal care (ANC) has been widely used to monitor trends of the HIV epidemic (40). Lesotho established a HIV Sentinel Surveillance (HSS) survey in 1991, at five sites around the country, where pregnant women seeking antenatal care were tested anonymously for HIV at their first visit. The 2007 HSS survey found that 27% of the pregnant women who visited a health facility for ANC were HIV positive (9). Both the 2004 and 2009 Lesotho DHS used biomarker data to measure HIV prevalence in the country. These data provide a current picture as well as trends over time.

In addition to collecting biomarker data, the surveys included questions about the experience of HIV testing. Figure 5 compares the percent age of the population that have ever tested for HIV, disaggregated by sex

Figure 5: Percent of population ever tested for HIV (15-49 years)



Data from the 2004 and 2009 Lesotho DHS (9,13)

and residence, for the 2004 and 2009 LDHS. There are four primary contexts of HIV/AIDS testing: mandatory testing; voluntary counseling and testing (VCT); routine testing; and diagnostic testing in the context of receiving individual medical care (41). Each approach to screening has a different set of standards associated with it. In the context of Lesotho, the focus on testing pertains to VCT and routine testing (also referred to as “provider-initiated” testing and “opt-out” testing). The provision of VCT has become easier, less expensive, and more effective over the last decade with the introduction of the rapid test which enables individuals to test and receive results in the same day (42). Various approaches to increase uptake of VCT have been tried including, mobile testing clinics to reach remote communities and incentivizing testing with the provision of prizes and rewards. However, there remains a low uptake of VCT in most SSA countries, including Lesotho. In 2004, the Lesotho DHS reported that 12% of women and 9% of men had ever had a

HIV test (13). In response to low testing rates, the Lesotho government has taken action to increase the number of its citizens getting tested.

Know Your Status Campaign (KYS)

In 2005, Lesotho developed a highly ambitious community-based HIV testing program, with the full support of the WHO, in which thousands of lay counselors were trained to administer door-to-door testing to everyone over 12 years of age (an estimated 1.3 million citizens at the time) over the course of two years. The kick off of the KYS campaign featured King Letsie III and Prime Minister Pakalitha Mosisili publicly testing for HIV. The program is regarded as the entry point to access prevention and treatment services, and is backed up by a policy of “routine offer” of HIV testing at health facilities. Lesotho was following in the footsteps of neighboring Botswana, in the adoption of routine testing policies and the implementation of national testing campaigns. Additionally, both countries were aligned with the policy debates and shifts occurring at the WHO at the time.

At the time of the launch of this campaign, Lesotho like many other SSA countries was experiencing a critical shortage of health care personnel; there were less than 90 physicians in Lesotho and only six out of the 171 health centers met minimum staffing requirements (43). The program utilized community-based lay health counselors to make up for this critical shortage, to access those hard to reach remote locations, and reach people who do not come into regular contact with the formal healthcare system.

The Lesotho KYS campaign fell short of its testing goals and was heavily criticized by the international community for failing to safeguard the human rights of its citizens. Twenty-one months into the program, an estimated 3,590 counselors had been trained out of the target 7,200

counselors. Additionally, by late August 2007, fewer than 25,000 people had tested through the KYS program, just 2% of the 1.3 million target by the end of that year (43).

The Human Rights Watch published a report in 2008 which found that in its quest to test every “household”, the campaign failed to ensure that each individual within a household is able to consent or decline to be tested. (39). Both pre- and post-test counseling were found to be inadequate as was linkages to care and treatment (43). Another cited shortfall of this campaign was that the government had budgeted \$12 million for testing, but only \$385 million for post-test referrals (39).

Although the continued trend toward task-shifting and the decentralization of services in Lesotho is crucial to dealing with severe shortages of health care personnel in the country, every effort should be made to ensure that lay counselors are well trained and monitored in the field. Community-based testing has potential in Lesotho and addresses the challenge of geographical isolation experienced by many of its citizens. The Human Rights Watch reported that the curriculum to train lay field counselors contained no guidance on informed consent, or what elements needed to be covered in pre-test counseling (43).

IX. Women and Testing In Lesotho

“Men are very reluctant to test. Sometimes they make the decision, and the women in the household can’t test. I just keep going back to such houses [hoping to encounter the woman alone].”
-KYS counselor (43)

There has been increased uptake of testing in Lesotho in the last decade. Table 1 shows the increase in women reporting testing for HIV from the 2004 and 2009 LHDS. An estimated 42% of adult women reported that they had been tested for HIV and received their results in 2009 compared to about 6% in 2004 (1). It is not clear if the test was provided at a facility or as part of a community-based testing program.

Table 1: Percent of females testing in 2004 and 2009 LDHS (44)

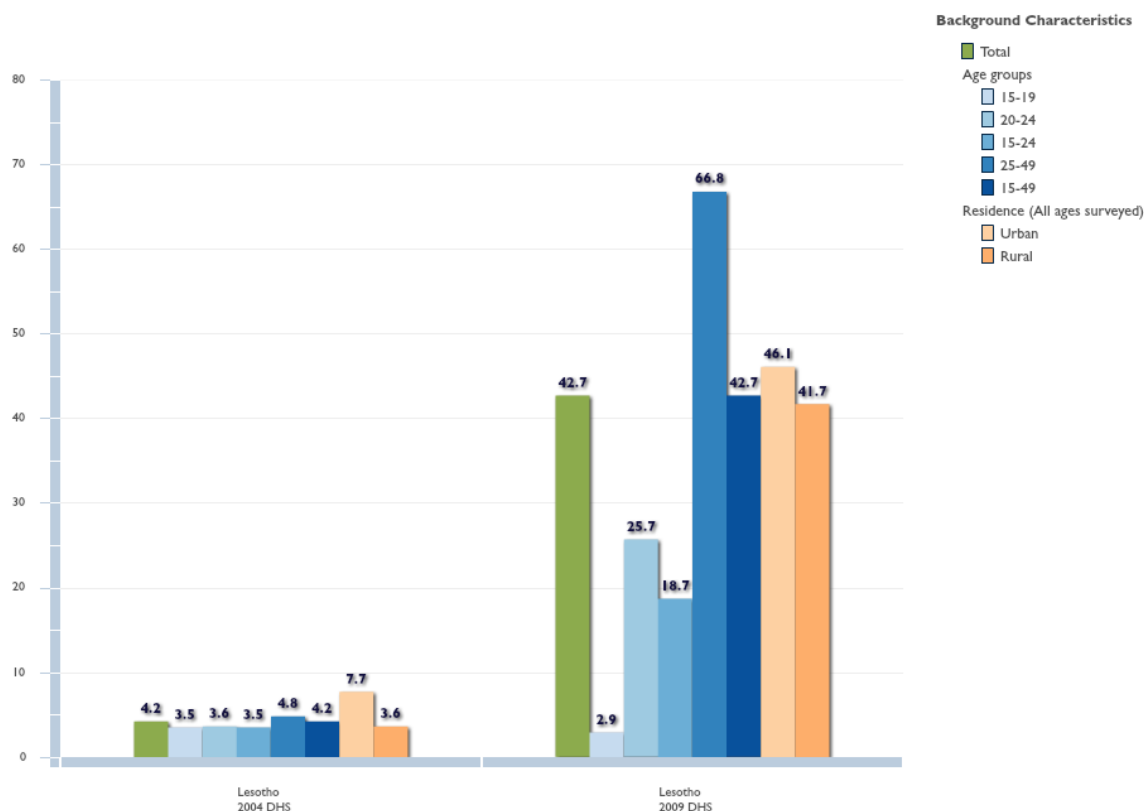
	Voluntary counseling and testing	Voluntary counseling and testing	Voluntary counseling and testing	Voluntary counseling and testing
	Population requesting an HIV test, receiving a test and receiving test results: Female	Population ever receiving an HIV test: Female	Population receiving an HIV test and receiving test results in the last 12 months: Female	HIV testing behaviour among young people, sexually active in the last 12 months: Female
Lesotho				
2004 DHS				
Total	8.0	14.5	6.3	7.2
Residence (All ages surveyed):	11.5	18.2	8.6	8.9
Urban				
Residence (All ages surveyed):	7.0	13.4	5.6	6.8
Rural				
2009 DHS				
Total	36.5	68.6	42.0	50.7
Residence (All ages surveyed):	39.8	68.9	42.1	47.9
Urban				
Residence (All ages surveyed):	34.8	68.4	42.0	51.8
Rural				

Routine testing in ANC

Another strategy to increase uptake to HIV testing is the adoption of routine and opt-out testing into national policy. Lesotho incorporated both these in its 2006 policy framework (45). DHS data collected before and after national policies promoting routine testing for HIV/AIDS depict the numbers of women who have been tested as part of an ANC visit (see Figure 6). The

population is limited to women who were pregnant at any time during the two years preceeding the survey.

Figure 6: Pregnant women tested for HIV during ANC Visit (44)



According to the latest UNGASS country progress report, the total number of women attending their first ANC visit has been steadily increasing from 24,651 in 2007, to 36,500 in 2010, and 37,418 in 2011. HIV testing coverage among pregnant women reached 69% in 2011 (5). The same report also states that Lesotho has been intensifying provider-initiated testing and counseling (PITC) to ensure that wherever a woman encounters the health care system, she takes

the opportunity to learn her status (5). Routine testing has been cited as problematic by human rights critics who point out that pregnant women who go in for an ANC visit do not necessarily do so in order to seek out an HIV test and therefore may be unprepared to handle a positive result (46).

X. Human Rights and HIV Testing

“Recent and justifiable interest in scaling up HIV testing has resulted in a discourse that is highly politicized and that once again appears to be pitting public health goals against human rights norms. We must not allow public health and human rights to be framed as diverging concepts.”

-Sofia Gurskin 2004 (47)

Ethical and human rights debates have surrounded HIV/AIDS testing since the first antibody test became available in 1985 (47). Activism campaigns emerged at the onset of the epidemic which set a global precedent (48). It is important to note that at this time, there was no treatment available for those who tested positive. By 1992, a broad consensus had emerged from international health governing bodies around ethical and human rights standards of HIV testing. This led to criticism from many clinicians and public health officials about what they referred to as the “exceptionalism” of HIV (47).

Testing guidelines focused on the three C’s of testing, namely: pre- and post-test counseling; confidentiality of test results; and (informed) consent. In addition to these, a right’s based approach to testing also includes such elements as non-discrimination in service delivery, linking the test to care, treatment and support, and a supportive social, legal and policy-

framework that protects people from potential harms associated with disclosure of status, and mechanisms for redress for peoples whose rights are infringed upon during testing. In 2006, the CDC revised their HIV/AIDS testing guidelines eliminating the informed consent component and shifted to a provider-initiated model. The following year, UNAIDS/WHO issued revised guidelines stated that, in generalized epidemics, such as Lesotho, HIV/AIDS tests should be given to all members of the population who have contact with a provider regardless of the reason for attending the health facility and whether or not the client exhibits signs or symptoms of HIV infection (49).

Shifting guidelines and policies resulted from other international initiatives surrounding treatment, care and support of PLWHA. The WHO adopted a “3 by 5 program” for HIV/AIDS, which set a goal to provide ART for 3 million people by 2005 (47). This declaration necessitated a massive scale up in HIV testing. Along with this initiative, the WHO declared at the 2004 International AIDS Conference in Bangkok that with treatment as a possibility, the offer of routine testing has become critical (47). This declaration was met with resistance by HIV/AIDS activists who fought since the beginning of the epidemic advocating for the human rights of HIV/AIDS in order to prevent such policies. However, not everyone in the public health community was opposed to routine testing of HIV/AIDS. One of the biggest proponents of this shift in approach was Dr. Kevin De Cock of the United Kingdom, who began to argue for routine testing of HIV/AIDS in 1996, ten years before the revised CDC guidelines were issued (47). Dr. De Cock advocated that all patients should be tested as part of a routine medical examination, unless they specifically declined to be tested. He argued that “informed right to refusal” was sufficient to meet ethical standards of consent (47). In a 2004 letter to the editors of *The Lancet*, the Human Rights Watch responded to Dr. De Cock’s call for more routine testing, by stating

that the reality of this policy in Africa would mean that more women and girls would be receiving the “opt-out” testing as they have more contact with formal health care systems than their male counterparts, placing them at risk of violence and abuse (50). The letter goes on to implore governments who adopt these policies to do so alongside well-funded, wide spread measures to protect HIV-positive women and girls from abuse (50).

WHO and UNAIDS disseminated new testing guidelines on May 30, 2007, which called for various sets of policies for different regions of the world. These guidelines were met with disagreement, caution, and harsh criticism by human rights activists and some international NGOs. That same year, the UNAIDS Reference Group publicly disagreed with its parent organization, UNAIDS, by stating their concerns that the “opt-out” policy approach would result in the practice of involuntary testing without informed consent (47). The international NGO, CARE, appealed that any new guidelines must consider the gender dimensions and the women’s ability to protect herself (47). The Global Network of People Living with HIV/AIDS voiced concern that the international community acknowledges stigma, discrimination, and violence as serious issues that affect those receiving a positive test; however they not accounted for in policy formation due to a lack of evidence (47).

Figure 6 (43)

Human Rights Watch cites five important aspects of HIV testing and counseling campaigns from the perspective of human rights principals and public health ethics (see Figure 6).

A 2012 publication analyzing national HIV testing policies of 19 countries adapts a UNDP tool for examining governments obligations to protect the

Five aspects of testing
1. Informed consent and counseling
2. Confidentiality
3. Linkages between HIV testing and prevention
4. Accountability mechanisms
5. The adequacy of the policy and legal framework for protecting the rights of people living with HIV

right to health, to create a human rights framework for analyzing HIV testing policies (51). This framework (see Table 2) incorporates the five aspects of testing and includes the following three components: obligation to respect; obligation to protect; and obligation to fulfill. Lesotho was not included in this analysis. Using this framework, Lesotho's most recent testing policies will be analyzed under each of the three components.

Table 2: Human rights framework for analyzing HIV testing policies (51)

Government Obligation	Components in framework for assessing HIV testing policies
Obligation to respect	<ul style="list-style-type: none"> • Opportunity to learn one's HIV status • Right to decline HIV testing without penalty of the health care setting • Assurance of confidentiality of testing results from third parties
Obligation to protect	<ul style="list-style-type: none"> • Insurance of adequate measures to protect from potential adverse consequences of testing and/or disclosing of one's status (including stigma, violence, and coercion of women's reproductive choices)
Obligation to fulfill	<ul style="list-style-type: none"> • Provision of counseling services • Access to adequate PMTCT services and follow up ARV therapy for herself and her child • Access to necessary psychological and support social services • Plans for implementation in order to create a conducive environment for women to get tested, decline testing, access treatment and care.

The most recent National HIV and AIDS Policy document was released in 2006. According to a 2009 document of partnership framework between the U.S. Government and the Government of Lesotho, the Ministry of Health and Social Welfare was in the process of revising national HIV counseling and testing policy to allow for couples counseling, and discordant couple interventions (20,52). However, updated policies could not be located. Information on policies

has been obtained from the 2006 National HIV and AIDS Policy document, the Lesotho HIV & AIDS National Strategic Plan (2006-2011), and a working draft of the Lesotho National ART Guidelines (45,53,54).

Obligation to Respect

In order to examine national HIV testing policies for evidence of the Government of Lesotho's obligation to respect (or not violate the rights of women), the primary focus will be informed consent and confidentiality.

Informed Consent

The WHO/UNAIDS guidelines recommend that providers inform clients about HIV testing through a pre-test information session that can be given either individually or in a group setting (46). In order for the client to decline a test, the client must explicitly state that they do not want to be tested. Replacing pre-test counseling with information sessions allows providers to recommend testing to clients without also explaining the risks and benefits associated with the test (46). Human rights advocates point to power differentials between the women that the health care provider as a potential barrier to women feeling that they can really “opt-out” of an HIV test (46). A study in Botswana, where “routine testing” was made widespread in 2004, showed that 69% of participants believed that they could not refuse the test (55). Additional research has shown that women may feel they need to test in order to receive services from their health care provider (51).

Reasons women give for refusing HIV tests include: fear of the test; fear of consequences of a positive test result; knowledge of the lack of availability of ART for herself; and the need to

consult a partner before testing (55). A lay counselor for the KYS campaign in Lesotho reported:

Women are afraid to tell their husbands. They fear beatings, insults.

They worry that disclosure will destroy peace in their house. Some men may start calling them names, accuse them of sleeping around (43).

Given that women, especially pregnant women, come into contact with the formal health care sector more frequently than men, they are often diagnosed with HIV before their male partners and tasked with disclosing that diagnosis. Therefore, they risk being blamed by him for bringing HIV into the partnership whether that is true or not (55). This leaves her susceptible to violence and abandonment by her partner. This process underscores the social/structural factors that link GBV and HIV and increased her vulnerability to acquire HIV infection in the first place.

Lesotho's National HIV/AIDS Policy identifies routine testing as vital for the prevention of mother to child transmission (PMTCT). The policy also states that guidelines for routine testing should be established by the government, and that guidelines should ensure informed consent. However, there is no further guidance as to how this consent should be obtained. The same occurs for provider-initiated testing (45). There is no explicit protocol mentioned in the policies about what to do if a woman refuses to test. At the 2008 International AIDS Conference in Mexico City, Lesotho's Minister of Health, Mphu Ramatlapeng stated that all women coming into contact with a medical facility will be tested for HIV, citing the interests of the unborn child. She went on to say that they can "opt-out" of receiving test results. Those who "opt-out" of receiving results will be counseled to accept and receive a follow-up visit by a health provider to her home (43).

Confidentiality

Lesotho's national policies use the word confidential in the definition of counseling which is referred to as a "confidential dialogue" (45). Additionally, confidentiality is mentioned in the context of the human rights and of PLWHA, in that they should be able to undergo prevention, care, treatment and support services with respect to their privacy and confidentiality. The term is used again with regards to STI testing, but does not appear in the sections directly pertaining to routine or provider-initiated testing.

The policy identifies beneficial disclosure as a component of the guiding principal of a public health approach to the epidemic (45). Beneficial disclosure is the notification of an individual's HIV test results to a partner. Disclosure is described as a sensitive issue in this section and the development of guidelines to "encourage and persuade" HIV-positive people to report to their partners promoted. However, this is followed by a statement calling for the legal authority of health care providers to inform sexual partners of an HIV-positive person's status. Furthermore, development of governmental guidelines and legislation of mandatory disclosure is advocated (45).

Obligation to protect

Lesotho's national HIV/AIDS policies stress the importance of protection for vulnerable and marginalized populations including women and PLWHA. Considering the evidence highlighting women's fear of violence resulting from testing and disclosure, it is concerning that GBV is not addressed in current national testing policies of Lesotho, and that there are no clear guidelines for protection in the move towards beneficial disclosure. Reference is made in the document to international human rights law as well as the Constitution of Lesotho which

guarantee the right to equal protection before the law and freedom from discrimination and provision of protection for vulnerable groups (45). However, it is important to keep in mind the dual role that customary law holds in the country as well as the lack of legislation regarding violence against women. Within the policy framework, it is acknowledged that it does not fully encompass some of the challenges related to gender inequality in the traditional context (45).

Obligation to fulfill

Counseling

Another point of concern about the routine testing guidelines from the human rights perspective is in regards to counseling. Although the guidelines explicitly state that post-test counseling should remain, the elimination of the pre-test counseling session raises concern. The provision of counseling before and after an HIV test has been demonstrated as an important mechanism to help positive individuals cope and both positive and negative individuals devise a plan of action based upon their results. Human Rights Watch points out that in order to make an informed decision about an HIV test adequate information must be provided through a pre-test counseling session (43). If this is not done, or if it is done poorly, this may result in a violation of the principal of informed consent.

The current WHO/UNAIDS guidelines de-emphasize pre-test counseling. The subsequent adoption of the guidelines into Lesotho's national testing policies elevates clinical intervention without addressing the social aspects and risks associated with testing women for HIV. It can be argued that only informing women of the benefits of testing denies her right to autonomous, informed decision making, thus rendering her choice-disabled (51).

XI. Conclusion

On World AIDS Day December 1, 2011, former U.S. Secretary of State, Hillary Clinton, announced a U.S. Government policy priority to create an AIDS-free generation. A highly effective, evidenced-based intervention, full coverage PMTCT services is crucial to achieving this vision. Integrated HIV testing as a part of routine ANC is the first step to implementation. HIV-positive women must be indentified in order to receive ART in a timely and effective way. Lesotho continues to expand the provision of PMTCT interventions to reach all pregnant women in every household and community in the country and PMTCT coverage reached 80% in 2011. In addition, the Strategic Plan for Elimination of Mother-to-Child Transmission of HIV and for Pediatric HIV Care and Treatment (2011-2016) was launched with the full commitment of all stakeholders to reach zero vertical transmission of HIV by 2015 (5). Lesotho's progress in PMTCT service provision and potential to attain full coverage is a remarkable achievement. Rather the social and structural context of Lesotho where these gains are being achieved should always be taken into consideration. Policies and programs should be examined through both a human rights and gender lens.

In his remarks on the same day, former Lesotho Prime Minister Pakalitha Mosisili commended Lesotho's momentum in combating HIV/AIDS and praised the KYS campaign for putting Lesotho on the international map and encouraging many people to overcome fear and test for HIV (56). Despite the documented failings of the KYS campaign, it is still being lauded by the government of Lesotho as an achievement, not as an opportunity to learn from past mistakes and inform better future testing initiatives. A lack of acknowledgment of the documented human rights abuses that resulted from the campaign should be met with skepticism; human

rights advocates should continue to campaign for policies and programs that uphold the rights of women.

Substantial gaps of information in national policies are another point of concern. Lesotho's National HIV/AIDS policy lacks clear guidelines and procedures for how to carry out its objectives of complete testing coverage. There is also a lack of clear plans for implementation and monitoring of these policies. If such plans and indicators exist, they should be clear and available to all decentralized governmental facilitates, implementing partners and stakeholders, and national and international NGOs. Testing guidelines and policies should not be written in dissonance with human rights, rather in harmony with them.

Recommendations

1. More research is needed.

There is little evidence specific to the country of Lesotho regarding the effects of routine testing on women living there. Qualitative and quantitative data should be collected to study this. Mix method studies need to be conducted in order to provide a platform for the creation of evidence-based policies and interventions for women and girls. Specifically, policies that promote the exclusion of pre-test counseling sessions should be reexamined in light of this new data.

2. The Government of Lesotho should be accountable for its commitments to international commitments and treaties to protect the human rights of women and pass and enforce a law criminalizing domestic violence.

3. National policies and HIV testing guidelines should be clear and meet the criteria of the human rights framework. These policies should be effectively monitored and evaluated.
4. Integrate gender into HIV testing and counseling services. All service providers and lay counselors should be trained in supportive strategies for women in testing, counseling and disclosure. Additionally, all providers should be trained in ethics and human rights.

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